

Adolescents' Experiences in Managing Type 1 Diabetes

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Abstract

Objectives – This study examined perceived changes in diabetes management among adolescents with type 1 diabetes as they transition from childhood to adolescence, focusing on self-management, parental involvement, physical activity, and treatment reflections. **Patients and Methods** – Qualitative description employing individual semi-structured interviews was utilized with 19 adolescents. Interview data were processed using a content analysis approach. **Results** – Most adolescents managed their diabetes independently, drawing from years of experience. While some adhered to medical advice, others made independent decisions, prioritizing convenience, or habits. Parental roles varied, from regular supervision to granting autonomy. Many adolescents appreciated parental support, feeling it provided security, though some experienced it as overbearing or insufficient. They had increased independence in managing their diabetes as they grew older. Acceptance of the disease improved with time, aided by technological advancements. Challenges included increased insulin needs and food intake during adolescence, but overall, they felt more confident and responsible in self-management. Despite advancements in technology, practical challenges persist in managing diabetes during physical activity. **Conclusion** – Adolescents with diabetes generally develop effective self-management skills and appreciate increasing autonomy, though adherence to medical advice varies. Continued parental support and advanced diabetes technologies play crucial roles in their management. Personalized treatment and balanced parental involvement are needed to increase adherence.

Key Words: Type 1 Diabetes ■ Adolescent ■ Physical Activity ■ Parental Involvement ■ Self-Management.

Introduction*

Type 1 diabetes (T1D) is one of the most common chronic diseases among children and youth worldwide. A comprehensive review and meta-analysis revealed that globally, the prevalence of T1D stood at 9.5%, alongside an incidence rate of 15 per 100,000 individuals (1). An estimated 1.2 million children and adolescents worldwide are living with T1D. Europe shoulders the greatest burden, with over 295,000 cases and the highest annual incidence of 31,000 new diagnoses (2). To date, neither the definite cause nor any way to prevent T1D are known (3). Although it can be quite well

managed and maintained with proper insulin therapy and nutrition, as well as regular physical activity, the adolescent developmental period is marked by deterioration in both adherence and metabolic control. Every adolescent with T1D adapts and responds to these changes differently, which can be challenging in treatment and care for the patient, parents, and healthcare experts.⁴ While successful diabetes management relies heavily on self-care, the behavioural shifts and emotional fluctuations that come with puberty can make it difficult for adolescents to stick to their treatment plans. Adolescents might also engage in riskier behaviours that can negatively impact their adherence (4, 5).

Central to their ability to cope with diabetes is effective family communication, which plays a

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critical role in supporting adolescents' self-management and overall well-being. Family communication encompasses the exchange of information, emotional support, and decision-making processes within the family regarding diabetes management tasks and the impact of the condition on daily life. Studies have highlighted the importance of open and supportive communication between parents and adolescents in fostering diabetes self-care behaviours and improving glycaemic control outcomes (6-8).

Recognizing the complexities of living with T1D during adolescence, efforts should be made to gain nuanced information from adolescents so that comprehensive support strategies can be developed to meet the changing needs of this population. Qualitative inquiry is a valuable tool for exploring the lived experiences and coping mechanisms of adolescents with T1D, and provides insights that inform the development of targeted interventions and support services.

The present study endeavours to elucidate the perceived changes in diabetes management among adolescents transitioning from childhood to adolescence, focusing on the evolving dynamics of self-management, parental involvement, physical activity engagement, and treatment reflections. This qualitative investigation aims to explore of their experiences, providing a foundation for tailored interventions.

Patients and Methods

Study Design, Patients and Ethics

This study employed a qualitative descriptive design and utilized voluntary response sampling to recruit adolescents clinically diagnosed with T1D for individual face-to-face interviews. Patients were recruited from one of the largest diabetes clinics in Hungary, which serves approximately 350 paediatric patients in the north-eastern region of the country. According to the WHO definition, adolescence includes individuals from 10 to 19 years old (9). Inclusion criteria were: ages between 12 and 19, to allow comparison of diabetes management between

childhood and adolescence, a diagnosis of type 1 diabetes before the age of 10, regular attendance at check-ups, living with diabetes for at least 2 years, and no major co-morbidities. Adolescents were interviewed in a separate room near the diabetologist's office while waiting for their check-ups during the winter of 2023-24.

The research was approved and registered prospectively by the B-A-Z County Central Hospital and University Teaching Hospital Regional Science and Research Ethics Committee under the registration number of BORS-18/2023. Parents and patients were informed about the study's purpose, methods, anonymity, and voluntary nature via email. Participation invitations were sent by the assistant at the clinic. Written informed consent was obtained from parents/or legal guardians. Interviews were only conducted with informed consent. Before commencing the interview, permission was obtained to audio-record the responses. All methods were performed in accordance with the ethical standards laid down in the Declaration of Helsinki and its later amendments or comparable ethical standards.

Interviews

Qualitative description employing individual semi-structured interviews was utilized. This approach is centred on providing clear and concise descriptions of the data, while staying closely connected to it, avoiding excessive theoretical extrapolation or abstraction (10, 11). Each interview lasted an average of 30 minutes and was conducted before a scheduled appointment or after the check-up. To ensure unbiased responses, no clinicians, allied healthcare professionals involved in patient management, and parents were present during the interviews. Prior to conducting the interview, patients were provided with information about the study's particulars, to reassure them regarding ethical standards, including anonymity and confidentiality (12). For keeping track of patients' answers, four thematic areas were explored with 13 pre-arranged questions, including self-management and adherence,

Table 1 Thematic Areas and Related Questions

Overarching themes	Interview questions
Self-management and adherence	What kind of diabetes-related problems do you find hard to solve? If you have difficulties with your diabetes, what do you do? How much do you accept and follow your doctor's advice?
Parental involvement and communication	How much do your parents allow you to manage your diabetes on your own? How much do you feel the need for parental supervision? Can you openly discuss your diabetes with your parents?
Physical activity and its impact	Do you engage in regular physical activity or participate in any sports outside of physical education classes? If yes, what kind of sport do you prefer? How much does your diabetes hinder physical activity or participation in sports?
Reflection on management over time	What are your experiences regarding managing diabetes during childhood and now in adolescence? Do you perceive any differences? During which period did you pay more attention to your blood sugar levels, childhood or adolescence? During which period did you pay more attention to your dietary recommendations?

parental involvement and communication, physical activity and its impact, and reflection on management over time. Table 1 presents the thematic areas and related questions.

Data Handling and Analysis

The interviews were audio-recorded and transcribed verbatim by authors (13). Each interview consisted of 13 questions. The transcripts were then imported into Microsoft Excel 2010 (Microsoft Corporation, Redmond, WA, USA) for data management and analysis. Each patient's responses were organized into rows corresponding to the interview questions, with columns representing individual patients. To ensure accuracy and reliability, two independent assistant researchers cross-checked the transcriptions against the audio recordings, resolving any discrepancies through consensus. The Excel spreadsheet served as a centralized repository for the raw interview data, facilitating easy access and retrieval during the subsequent analysis phase. The analysis was guided by the content analysis approach of Elo and K yng s (14).

Results

Patients

Thirty-one parent-child dyads expressed interest in participating, but either did not attend the

scheduled appointment, or the child arrived alone without parental consent. A total of 19 interviews were conducted with children. Seventy-four percent of patients were girls, with an average age of 14.95 (SD=1.58) years. Their average disease duration was 9.26 (SD=2.64) years, and their average HbA1c level was 8.72 (SD=2.01) mmol/L. Patients received various treatments for diabetes management, including insulin pens, insulin pumps, and continuous glucose monitors (CGMs). Treatment regimens varied among individuals: some used insulin pens exclusively, while others used insulin pumps alone or in combination with CGMs. No medication other than insulin was administered. The majority of patients had moderate glycaemic control. The sex ratio of enrolled participants was skewed towards girls, the mean HbA1c levels and the distribution of treatment regimens (pen, pump and CGM) did not differ significantly between the adolescent patients at the centre and those in the study group. Detailed demographics and clinical status are provided in Table 2.

Findings of Interviews

Self-Management and Adherence

Most adolescents believed they had faced no significant difficulties and could handle them alone if they arose. Having lived with diabetes for several years, they had learned to manage situations arising from the disease.

Table 2 Participants' Demographics and Clinical Status

Interview order	Gender	Age	Age diagnosed	Time since diagnosis	HbA1c mmol/L	Severe hypoglycaemias in the past month	Treatment
1	Girl	14	7	7	7.0	0	Pen+CGM
2	Boy	12	5	7	7.7	5	Pen
3	Girl	14	6	8	14.0	0	Pen+CGM
4	Boy	15	5	10	6.9	0	Pump
5	Girl	15	3	12	8.6	0	Pump
6	Girl	13	8	5	9.2	0	Pump
7	Girl	16	9	7	8.1	0	Pen
8	Girl	13	2	11	7.2	0	Pump
9	Girl	16	5	11	8.1	0	Pen
10	Girl	17	6	11	11.2	0	Pump+CGM
11	Girl	14	3	11	8.2	0	Pump
12	Girl	16	3	13	8.0	4	Pen
13	Boy	17	3	14	7.9	0	Pump
14	Boy	16	9	7	7.3	0	Pen+CGM
15	Girl	15	5	10	7.6	0	Pump+CGM
16	Girl	14	4	10	10.0	1	Pen+CGM
17	Girl	13	9	4	7.1	5	Pen
18	Boy	17	8	9	8.5	0	Pump+CGM
19	Girl	17	8	9	13.1	0	Pen+CGM

Pen=Including insulin pen; Pump=Insulin pump; CGM=Continuous glucose monitor.

"I've got used to everything and managed to incorporate it into my daily life." (Patient (P) 13)

"I don't think there's anything that would cause me unsolvable difficulties." (P 6)

"I always have glucose and insulin with me, even if I'm just going to the store." (P 19)

Some mentioned they managed hyperglycaemia well but struggled more with severe hypoglycaemia, occasionally alerting their parents to the situation. However, some did not require assistance even in such cases.

"I can pay attention to myself so much that I don't need anyone else's help." (P 5)

"I don't have a problem with high values, but when they're very low, it's good to have someone around." (P 7)

"I tell my mom. Usually, I can handle it alone, but if my sugar is very low, then I tell her." (P 9)

"Getting out of bed at night and getting something sugary to eat, that's the challenge but I can control it." (P 3)

Many adolescents did not always follow the advice of their treating physician, making independent decisions or overriding medical advice. While many attempted to adhere to it, factors such as convenience, laziness, or established habits sometimes hindered success.

"I try to adjust to what the doctor says because he's the professional, but sometimes in a specific situation, I know it won't be good. Then I do it my way, which I believe will lead to a slightly better outcome." (P 16)

"I often follow my own head, which I regret later. When I make my own decisions, my sugar often goes off track." (P 6)

"Sometimes I stick to it, sometimes not. Most of the time, I rely more on my own experience." (P 10)

Parental Involvement and Communication

We encountered both extremes when questioning children about parental supervision and support.

Most stated that their parents allowed them to manage the tasks associated with the disease, but occasionally checked to ensure everything was alright. This allowed parents to be informed if any problems arose. Apart from three children, everyone indicated that they could discuss the disease with their parents without difficulty. One child mentioned that it was much harder for her mother to accept the disease than for herself, so they avoided the topic. From the ages of 10 to 12, they felt that their parents had entrusted them with managing the disease and felt responsible for it. While children welcomed independence, the responses suggested that parental support provided a sense of security. If something went wrong, the parent was there to help and provide advice. Nevertheless, some children still felt under strict parental control, which they either accepted or were forced to accept, while others felt that their parents no longer cared, which did not sit well with them.

“From the age of 10, they (parents) began to let me handle my illness. I have been sick since I was 3, so I grew up with it, and they already saw that I don’t need much help and I can manage it myself.” (P 13)

“They still check on me. I think it’s good because if I’m doing something wrong, they correct me.” (P 9)

“Actually, my mom always watches over me, and so does my dad, but about 4 years ago they started letting me do it myself. I must learn to do it when I’m an adult and they can’t help me.... It’s scary responsibility.” (P 11)

“When I was little, around 10 years old, my mom had to help me because I was afraid to inject myself. From the age of 14, they completely let go of my hand, and since then I’ve had a pump too. They rarely ask how my sugar is, but they’re not very interested anymore. It’s better for me this way, at least they don’t get on my nerves so much about why my sugar is bad.” (P 10)

Physical Activity and Its Impact

Half of the patients indicated that they engage in regular physical activity outside of school physical education classes. They engage in various types of movement, such as handball, volleyball, swimming,

horse riding, jogging, conditioning, wall climbing, and dancing. Some said they bike, rollerblade, and hike in the summer, but not on a daily or weekly basis. Hypoglycaemia tends to be a problem, but in practice they have already learned that they need to consume more carbohydrates before exercising. Overall, they do not see exercising as a difficulty, nor do they think that it would hinder them from engaging in physical activity.

“No, it doesn’t hinder anything.” (P 12)

“There’s a new PE teacher now, I told him what the situation is. He said that whatever happens, I can go out. But I pay attention to my sugar, so I can do everything. If it’s lower, then I eat, and if it’s higher, of course, exercise brings it down more, so I’ve learned that too.” (P 14)

“At most, when I exercise, my sugar drops a lot, and that’s very annoying, it drops no matter what I do.” (P 12)

“When I exercise, I have to take off the insulin pump and, of course, the signal is always lost, and it’s very troublesome to get it back.” (P 11)

“I don’t have any particular problem; my sugar rarely drops.” (P 4)

“... it’s just that my sugar drops very quickly from exercising.” (P 15)

“It doesn’t really cause a problem, just that I have to eat extra before even if I’m not hungry, but I’ve already solved this.” (P 19)

Reflection on Management Over Time

Several observations and experiences emerged during the conversations about the differences in management between childhood and adolescence. Many felt that they became more independent in managing their condition during adolescence, less dependent on parental attention. Acceptance of the disease became easier in adolescence, and many believe they handle life easier. However, at the beginning of treatment, many found it harder to accept the disease, but over time, acceptance and processing became easier. With the development of technology, treatment has become easier, but many remember that blood sugar levels were more stable in the past. With adolescence comes an increase

in food and insulin requirements, posing new challenges in treatment. Some adolescents find it easier now because their parents bother them less about issues related to the disease. With increasing autonomy, they become more actively involved in treatment and take responsibility for themselves. These observations indicate that treatment dynamics change with adolescence, and for many, this represents a developmental process in accepting and managing the disease. There were children who did not perceive significant changes in treatment depending on age.

“I can’t really tell you how the process went. It might have been simpler when my parents were watching over me, now I’ve become a bit more independent.” (P 1)

“Both (ages) are easy if you get used to it. I didn’t feel any change.” (P3)

“Never, it’s never easy with this. I don’t know. Maybe now, but maybe it was easier before, because back then I didn’t take it so seriously.” (P 12)

“When I was a child, blood sugars were much more stable. Much less insulin was needed then. Obviously, it’s much harder this way, but it’s also easier because technology is constantly evolving. There were no sensors then, and you had to pay attention every day, measure more times, but it was easier to manage either high sugar or hypo.” (P 13)

“My earlier self was irresponsible, I didn’t really care because I thought my parents were watching and they would say something if there was a problem. Now, I don’t like it when they interfere, of course, I listen to them, and they listen to me, but I prefer to do things myself.” (P 15)

Discussion

The aim of this qualitative study was to explore the experiences of adolescents living with T1D with many years, and to identify perceived differences in disease management between childhood and adolescence. We also focused on investigating the challenges encountered by adolescents, their attitudes toward their illness, and the significance they attribute to parental support in managing the disease. The findings reveal that adolescents generally feel

adept at managing their diabetes, integrating it into their daily routines. Many expressed confidence in handling diabetes-related challenges independently, indicating a sense of mastery acquired over years of experience. By adolescence, they were already feeling the weight of responsibility for managing their illness and wanted autonomy, which is in line of Ingersgaard et al.’s findings (15). The study by Wu et al. underscores that adolescents with diabetes were more successful in managing their condition when they received increased support for fostering independence (16).

However, the issue of adherence to medical advice emerged as a complex aspect of self-management. While adolescents acknowledged the importance of physician guidance, they also admitted to exercising autonomy in decision-making, occasionally deviating from prescribed protocols based on personal judgment or convenience (17). Adolescents appreciate their parents’ support in decision-making; however, they often prefer their parents to have a less prominent role. Nevertheless, background parental care, attention, and communication instil confidence in them (18). To mitigate the difficulties of procedure for transition of diabetes management from parents to adolescents, it is crucial to ensure continuous support, tailored education, and a gradual shift of responsibility that respects the adolescent’s growing desire for autonomy, while providing the safety of parental and professional support. Addressing any misunderstandings or conflicts early through open communication and setting clear expectations can also help ease the transition.

While most participants expressed confidence in their ability to manage diabetes-related challenges, their relatively high HbA1c levels suggest that this self-reported competence does not necessarily translate into optimal glycaemic control. This discrepancy may reflect several factors, including an overestimation of their own management skills or difficulties in consistently applying effective self-management practices. Adolescents may feel competent in handling day-to-day aspects of diabetes, such as recognizing symptoms or adjusting insulin

doses; however, they may still struggle with achieving sustained glycaemic control.

Physical activity emerged as a cornerstone of diabetes management, with many adolescents actively engaging in various forms of exercise. Despite challenges such as hypoglycaemia, participants demonstrated adaptability by employing strategies to mitigate risks and avoid hypoglycaemia during exercise. Notably, advancements in technology, such as insulin pumps and CGMs, have facilitated greater flexibility in managing diabetes during physical activity. However, logistical issues, such as pump detachment during exercise, highlight the on-going need for technological education to address practical challenges faced by adolescents (19). Physical activity plays a crucial role in diabetes management, particularly in youth with T1D, as demonstrated by Gal et al.'s findings. Although we cannot draw definitive conclusions from our results, the literature suggests that engaging in regular physical activity is associated with improved glucose control and increased time in range (TIR) without substantially raising the risk of hypoglycaemia (20).

The transition from childhood to adolescence represents significant changes in the perception and management of diabetes. Adolescents tend to experience increased autonomy and acceptance of their condition, accompanied by a growing emphasis on self-management. While technological advancements have undoubtedly simplified certain aspects of treatment, adolescents often encounter challenges such as fluctuating blood glucose control and heightened insulin requirements during this period. This aspect of adolescence presents a challenge in terms of regulation due to the intricate biological transformations taking place during this developmental stage (21). However, it is noteworthy that individual experiences vary widely among patients, underscoring the personalized nature of this transition process. It highlights the importance of recognizing and addressing these dynamic changes in diabetes management as individuals progress through different stages of life.

The findings of this study have to be seen in the light of some limitations. The sample was drawn

from a single paediatric diabetes clinic in a specific region, potentially limiting the generalizability of the findings to broader populations of adolescents with type 1 diabetes. Additionally, the study relied on self-reported data, which may be subject to recall bias or social desirability bias, potentially influencing patients' responses. Moreover, the study focused solely on adolescents' perspectives, without incorporating the viewpoints of parents or healthcare providers, which could have provided additional insights into the dynamics of diabetes management during adolescence. Future research should consider including multiple perspectives and recruiting patients from diverse geographical locations to enhance the representativeness of findings.

Conclusions

Adolescents with type 1 diabetes face complex issues of self-management, parental involvement and physical activity during the transition from childhood to adolescence. Although many adolescents show resilience and adaptability in managing their condition, challenges such as adherence to medical advice and fluctuations in blood glucose control remain. Open communication between adolescents and their parents, and personalised support strategies are essential to promote independence and empowerment in diabetes management. Despite advances in technology, adolescents continue to face practical challenges in controlling blood glucose levels. Understanding the unique experiences and perceptions of adolescents with type 1 diabetes is key to developing targeted interventions and support services to optimise their health (22).

Availability of Data and Materials: All studies and data analysed during this study are included in this article. Further enquiries can be directed to the corresponding author.

Conflict of Interest: The authors declare that they have no conflict of interest.

Authors' Contributions: Conception and design: AL and ED; Acquisition, analysis and interpretation of data: AL and ED; Drafting the article: AL; Revising the article critically for intellectual content: AL and ED; Approved final version of the manuscript: AL and ED.

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